

Palliative Care Planning Group Wales

Report to the Minister for Health and Social Services

June 2008

All Wales Palliative Care Planning Group

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Foreword by Vivienne Sugar – Chair of the All Wales Palliative Care Planning Group

This report presents the findings of a dedicated palliative care Planning Group, Chaired and supported by the Welsh Consumer Council. The working group met for the first time on 21st November 2007 and subsequently met a further four times. A schedule of the groups' work can be seen at **Annex 1**.

Adult palliative care is discussed in Part One and Children and Young People's palliative care in Part Two. A combined set of recommendations is presented on **page 5**.

The field of palliative care is served by dedicated and hardworking individuals, many of whom recognise the importance of working as one team, irrespective of whether they are employed by the NHS or independent sectors. The patient does not need to know who delivers their care, only that they will follow a seamless care pathway. This strong theme of joint working is vital to the success of palliative care services in Wales and needs to be the driving force for the future.

This was an ambitious task for a very short timescale. Some of the issues raised were either outside our remit or require deeper analysis. However, we have flagged up all the key issues brought to our attention.

I would like to thank all members of the working group for giving their time so generously and to those who attended the workshops and submitted written evidence, the hospices who arranged for me to visit and last but not means least Rebecca Thomas and the team at the Welsh Consumer Council.

The terms of reference specified by the Minister for Health and Social Services when commissioning this work in October 2007 were:

1. To specify the elements of a core palliative care service including end of life care for (i) *adults* and (ii) *children* which should form the basis of a commissioning specification to underpin funding considerations by the Welsh Assembly Government and Local Health Boards.
2. To develop a means of formally measuring the quality of a core palliative care service which the Welsh Assembly Government and Local Health Boards can use to inform funding considerations for individual providers
3. To take evidence from organisations, service providers, individuals and written documents as it was deemed necessary to inform this work.
4. To conclude this work in time to inform commissioning and funding decisions from 2008-09.



Vivienne Sugar

Chair of the Palliative Care Planning Group Wales

Definitions of Palliative Care

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.
National Institute for Clinical Excellence.

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.”
ACT and the Royal College of Paediatrics and Child Health (RCPCN), 1993

Palliative care itself can be split into two categories, within which there are a number of important and varied roles.

- General palliative care: Delivered by Health Professionals in a generalist setting.
- Specialist palliative care: Delivered by Specialist Multidisciplinary Teams dedicated to palliative care

This care can be delivered in the following settings by a number of partners from the public (NHS and Local Authority services), private and voluntary sectors.

- a hospital setting (from general nursing to specialist palliative care teams working within a district general hospital),
- a hospice (either independent hospices or NHS hospices),
- in the home (through general palliative care providers such as District Nurses or specialist hospice at home services)
- in local community settings (such as daycare facilities, community hospitals, residential and nursing homes)

Executive Summary

The All Wales Palliative Care Planning Group was set up by the Minister for Health and Social Services to establish the elements of a core palliative care service for children and adults, and a means by which the service will demonstrate quality.

Following a short but extensive review, the group identified where the gaps were in service provision and some of the barriers that exist in the current system. The final recommended All Wales Core palliative care Service reflects the most recent research findings as well as the views of all those consulted. It is intended to provide equity of access to services for all palliative patients in Wales.

The report discusses the issues relating to Children and Adult palliative care separately with combined recommendations on **page 5**.

Palliative care services in Wales are delivered by a wide network of providers and, although there are many examples of good services across Wales, not all patients can access them. This is largely due to geography and understaffing in services, but there are a number of other factors discussed in the report.

In order to achieve the minimum service level, substantial investment is needed. Central funding must first be made available to all providers of the core service, both statutory and voluntary, to ensure a level playing field across Wales.

There are many problems with the existing commissioning process and no consistency in the way services are commissioned. In order to ensure better planning and sharing of services, the report recommends a move to regional commissioning for adult care and central commissioning of paediatric services, within an All Wales robust commissioning framework.

Although the review found the current means of measuring quality was of a high standard, it was not applicable to all providers of care, as defined by the core service. The report advocates a single regulatory body for inspection. These inspections must cover all clinical governance systems, and include facilities that provide inpatient and day care and nursing homes.

Training and education was emphasised as a driver for quality. The report recommends the setting of standards and co-ordination of training and education for all specialist and generalist providers to be developed across Wales.

Additional recommendations include, for example, the development of IT systems and the development of all Wales standard guidance.

The review itself has developed the blueprint for a core service, but much work needs to be done to ensure all patients in Wales can access that service. However, identifying the core elements is a positive and firm first step to establishing a robust and equitable service.

A core palliative care service must be holistic and put the patient at its centre. In line with NICE guidance and the outcome of the review, it should:

- provide all patients with a 24hr service across all parts of Wales
- provide all patients with a comprehensive needs assessment undertaken by an appropriately trained professional
- provide patients with the necessary treatment delivered through an appropriate setting
- provide patients with detailed information about their conditions
- ensure services are of a recognised standard and well co-ordinated
- recognise the importance and contribution of community, primary and secondary care and independent hospice services
- provide good symptom control
- provide psychological, social and spiritual support
- endeavour to enable patients to die in the place of their choice and offer support to families and carers through the illness and into bereavement

The following recommendations have been developed after extensive consultation and evidence gathering exercises undertaken by the group. The core service has been designed in line with the comments and testimonies of stakeholders.

Recommendations

The following recommendations are within a suggested timeframe of either short term (12 months) or medium term (1-3 years) dependent on the complexity of each recommendation. The prioritisation of these recommendations is to be determined by future work arising from this report, and the following timescales are a guideline only.

The work to be taken forward should be done so by a working group that includes both service provider (statutory and independent sector) and patient representation, including providers and users of children and young peoples services as well as adult services.

Short term (12 months)

- Establish an All Wales network to co-ordinate existing expertise, including representation from cancer, renal and cardiac networks, and organisations concerned with life limiting conditions for;
 - Children and Young People's palliative care
 - Adult palliative care
- Identify priority areas for action as arising from the findings of this report, for example consultant numbers for adult and paediatric care.
- Provide initial investment to achieve a minimum core service level across Wales and across all sectors for both adult and paediatric palliative care services.
- Use the core palliative care service level as a basis for distributing additional funding to the voluntary sector.
- Strengthen and improve the existing Continuing Healthcare process and ensure the current review of this guidance considers mechanisms for rapid access to funding and more flexible processes for application and renewal of equipment.
- Agree an All Wales standard guidance for all palliative care services, building on the current Welsh Cancer Standards, that sets out the core service specification with requirements that the core service be established in a set timeframe.
- In order to develop or nominate one single template, undertake an all Wales review of the templates used for;
 - i) individual care pathways
 - ii) patient pathway through services

Medium term (1-3 years)

- Establish a 24 hour secondary and tertiary support service for professionals across the whole of Wales (for both adult and paediatric services) using staff from the specialist palliative care team who have access to an on call consultant.
- Produce a separate circular for adult palliative care commissioning guidance, including:
 - mechanisms for approval of and continuing support for new services
 - agreed service specifications
 - arrangements for provision of care by the private sector
 - arrangements for pooled budget arrangements
 - arrangements for reimbursement for NHS and Local Authority provision
 - arrangements for reimbursement for voluntary sector provision
- Develop an All Wales Training and Education Programme with agreed Standards for all palliative care Providers in the following settings:
 - Primary Care
 - Secondary care and community hospitals
 - Nursing and Residential Care Homes
- Nominate a single regulating authority for inspection of all core services and develop inspection regimes for all clinical governance systems with peer review against agreed standards.
- Collate all Wales data on patient numbers and conditions to be used to inform commissioning and form a register of need.
- Develop information for patients, families and carers at a network level, including a directory of services.
- Develop the current IT systems for adult palliative care and establish an IT system for children's palliative care.
- Conduct further work to identify the specific needs of adolescents and young adults and nominate a member of the palliative care network to liaise with all networks on transition issues.

Methodology

Literature review

In order to build up an accurate picture of the current provision of palliative care in Wales, an extensive literature review was undertaken. This included all recent reports and guidance. This is discussed on **page 11** for Adult palliative care and **page 26** for Children and Young People's palliative care.

Expert evidence

For adult palliative care, expert evidence was taken from Peter Tebbit (National Council for palliative care), Ruth Treharne (Director of the South East Wales Commissioning Unit) Professor the Baroness Ilora Finlay of Llandaff (Professor in Palliative Medicine), Walter Brooks (former Chief Executive of St Michael's Hospice) and Hazel Cheeseman (Help the Hospices Policy and Public Affairs Officer for Wales).

For children and young people's palliative care, expert evidence was given by Jayne Saunders (Director of Care for Tŷ Hafan Children's Hospice), Katrina McNamara-Goodger (Association for Children's palliative care (ACT)), Patricia O'Meara (Paediatric palliative care Nurse Specialist) and David Featherstone (Chief Executive of Hope House Children's Hospices).

Written consultation

A general consultation exercise was conducted and around 300 organisations were invited to submit evidence. In addition, a webpage was set up for evidence to be submitted and invitation to participate was circulated in the Welsh Consumer Council's e-newsletter.

The consultation letter asked that the following questions be considered. A full copy of the letter can be seen at **Annex 2**.

- *What palliative care services should be funded by the NHS and/or Welsh Assembly Government and why?*
- *What services do you think should be funded by other means (i.e voluntary / private sector) and why?*
- *How can we measure the quality of these services?*
- *If you are a service provider, please give us a clear picture of the services you deliver, your experience (if any) of commissioning services and whether or not those services are readily available and sufficiently funded.*
- *If you represent service users, please give us a clear picture of the range of services you are aware of and how accessible and easy to use that service is, for example how far away is your nearest facility and is it easily accessible?*

The total number of written responses received was 61. Responses were representative of a range of services and a wide geographical spread.

The exercise and findings are discussed on **page 12** for Adult palliative care and **page 27** for Children and Young People's palliative care.

Workshops

There were around 130 attendees at the workshops, with a wide range of representation. This included social services, Local Health Boards, NHS Trusts, Nurses, Consultants, Carers' representatives and both smaller and major voluntary sector providers. Five workshops were held in total. Three discussed adult palliative care and these were held in South, Mid and North Wales. Two discussed children and young people's palliative care and were held in North and South Wales. A detailed discussion of the workshops can be seen at **Annex 4**.

Members of the group also spoke to the North Wales Cancer Network Patient and Carer Liaison Group.

Visits to hospices

During the review, the Chair of the group also visited a number of hospice organisations in order to see first hand the facilities and the work they undertake.

- Tŷ Gobaith Childrens' Hospice, Conwy (North Wales)
- Tŷ Hafan Children's Hospice, Vale of Glamorgan, (South East Wales)
- Beacon of Hope Hospice at Home, Aberystwyth, Ceredigion, (Mid Wales)
- Marie Curie Holme Tower Adult Hospice, Penarth, (South East Wales)
- Tŷ Olwen Adult Hospice, Murrison Hospital, Swansea NHS Trust, (South West Wales)
- Nightingale House Adult Hospice, Wrexham (North Wales)

Adult Palliative Care

1. Background research

There is an existing body of research and guidance on palliative care, much of which forms a good basis for a core palliative care Service. However, guidance is not always adhered to and there is an overabundance of documents. There is no single All Wales standard for service providers to work to.

A number of common themes emerge from the documents regarding patient need and considerations for commissioners.

The main themes are summarised below and form the starting basis for establishing a uniform service across Wales.

Key points

- Care should be holistic and always cover the key elements of physical, social, psychological and spiritual well being.
- The use of multidisciplinary teams is widely advocated as it ensures quality and continuity of service.
- The multidisciplinary team should provide patients with detailed information about their conditions, ensure services are of high quality and well co-ordinated, recognise the importance of community services, provide symptom control, provide psychological, social and spiritual support, enable patients to die in the place of their choice and offer support to families and carers through the illness and through bereavement.
- There should be 24 hour access to specialised support for general staff as well as information for carers.
- Community based services require further funding and development and are believed to not only provide cost effective services but also quality services.
- Care pathways should always be used and these must be driven by the needs of the individual patient, for example the All Wales Integrated Care Pathway for the Last Days of Life (see **Annex 3**).
- Education and training of staff is vital to ensure quality of service.
- Access to information and support for patients and carers is of great importance.
- Public sector funding for the voluntary sector is not sufficient.
- Insufficient services can lead to unnecessary admissions to hospital.

2. Analysis of Consultation Responses and Workshops

2.1 Access to Services

There was a feeling that more emphasis was placed on Palliative Cancer Services than non-cancer and that patient need should determine service priorities rather than the specific diagnosis. It was also felt services need to build in enough flexibility to allow patients to dip in and out when required, ensuring continuity of care.

There are specific problems in rural areas when accessing services. Respondents suggested that more community services and quicker discharge to community settings are needed in rural areas. In addition, the current public transport system in these areas does not support patients who need to access facilities. Taxi voucher schemes were one suggested solution to this.

Another geographical issue was cross border services. For adult palliative care, patients who wished to access inpatient hospices travelled across the border when there were no local services available. This was mainly applicable to Mid Wales. This needs to be recognised in the planning and commissioning of services.

2.2 Gaps in Services

Respondents noted a lack of day care facilities in some areas and that not everyone had access to specialist inpatient beds. Accessing emergency respite was highlighted as a particular problem.

Funding and access to equipment is often limited and the process by which equipment is accessed leads to unnecessary delays. Some areas have joint stores with social services, but most areas reported problems with the current way of working.

A directory of services was a suggested option, enabling staff and carers to identify and contact service providers in their area, and also highlight any gaps in the overall service.

Where services are available, there are not always enough staff to deliver them. There aren't enough staff to allow rapid response teams to develop, the numbers of skilled community nurses across Wales are insufficient, some areas lack consultant input and key workers aren't always available to patients. Another common concern was the effect that the reduction in district nursing numbers had on the ability to deliver general community services and that there aren't enough occupational therapists and physiotherapist places to fully serve the needs of palliative patients across Wales.

2.3 Technology

The current IT systems need further development, need to be more uniform and should be linked to the unified assessment process. This will ensure access to up to date individual patient records at all times.

There is a significant role that can be played by telehealth and telecare systems, not only in discussing treatment and care but also for the training and development of staff, for example through videoconferencing. This could be of particular use to staff in more isolated areas as it reduces travel time.

2.4 Multidisciplinary Team

The majority of responses advocate a Consultant led multidisciplinary team to deliver palliative care, and this must be core funded. The elements of this team include Doctors, Nurses, Physiotherapists, Occupational Therapists, Pharmacists, Social Workers, spiritual care workers and Welfare Rights Workers.

The current way of working means much of the out of hours services are delivered by staff who lack the relevant skills. Out of hours support should be delivered by General Practitioner (GP) or District Nursing (DN) staff who have been sufficiently trained in palliative care and have access to 24/7 specialist support and advice. This must also include access to medication at all times.

The services most believe should remain funded by the voluntary and private sectors were social support groups such as ongoing bereavement support, complementary therapies, additional services such as hairdressing, holidays and sitting services and some volunteer transport.

What was less clear was where bereavement and respite services should fit, as some felt the voluntary sector should provide this, some felt this should be a core element of a palliative care Service and some felt it should be a separately commissioned wider service for all those affected by bereavement.

Additional observations were that some conditions require greater support (for example Parkinson's or certain respiratory or renal conditions) as patients are suffering due to a lack of awareness and understanding of the needs associated with such illnesses. In some cases, this has resulted in poor planning for patients with these conditions. Improved data collection on patient numbers and conditions is needed to ensure services plan and account for these needs.

It was also suggested that greater investment is needed in the training of nurses in the independent sector, for example care home nursing staff. They could have a future role to play in a multidisciplinary team.

It was noted that greater psychological support is needed for staff and carers, as many struggled not only with the psychological impact of the nature of their job but also with the pressures of very demanding workloads.

2.5 Joint Working

There needs to be better working between services, especially between health and social services. This also needs to apply across geographical boundaries, and neighbouring local health board areas should share services and avoid creating artificial barriers within a regional area. As one respondent noted, it doesn't matter to patients who delivers the services as long as the service is delivered.

A number of respondents also noted that closer working relationships are needed with GPs.

2.6 Quality

There were a number of suggestions as to how quality could be measured and audited. Current inspection regimes were felt to be a good indicator of quality, such as Care Standards Inspectorate Wales and Health Inspectorate Wales. Also, the current National Institute for Clinical Excellence Guidance '*Supportive and palliative care for Adults with Cancer*' was felt to contain sufficient quality indicators.

Outcome led services were felt to be a mark of quality and the indicators for this varied, though many suggested that meeting preferred place of death targets was vital.

Agreed standards, such as the Gold Standards Framework, were praised and suggestions were made for All Wales standards. Care pathways need to be used to identify need and must be flexible so that services can respond quickly to peaks and dips in the level of care required.

Almost all felt patient, family and carer feedback was a vital component, be it through one to one discussions, surveys or focus groups. The user group did note that it felt questionnaires were an inappropriate tool and that patient diaries may be a better means of gathering patient views.

Training and minimum skill levels were felt to be a good quality indicator and suggestions were made for compulsory training, particularly for GPs, District Nurses and in care home staff. It was felt more opportunities for training must be made available for generalist staff such as Nurses, Healthcare Assistants (HCAs) and Allied Health Professionals (AHPs) to improve the quality of services delivered.

2.7 Commissioning

The majority agreed that changes need to be made to commissioning arrangements and that a more robust system should be in place. There was no clear consensus on how commissioned services should be funded. Some felt that any service commissioned by the NHS should be funded by the NHS, and many felt that short term grants did not allow for sustainable long term planning.

Many voluntary sector providers did express the view that they did not want over 50% funding as it may compromise their independence, yet the current overall percentage of funding they received was very low and must be raised.

The majority called for All Wales commissioning guidance and processes and almost all reported poor joint working between providers and Local Health Boards. Whilst some providers report they have agreed arrangements with the Boards, not all providers have Service Level Agreements in place. Many felt the level of funding they received for providing service was insufficient, and note this is not based on a formula or needs basis, but simply an arbitrary contribution that is increased year on year. Suggestions were made that services should be funded on a regional basis but at the very least, there needs to be a uniform commissioning process in place if Local Health Boards continue to act as the Commissioner.

There were suggestions for pooled budgets for joint Health and Social Care services, such as respite services or complex care packages, to avoid delays in accessing funding. Many providers noted problems with the Continuing Healthcare mechanism, stating it was bureaucratic, often misinterpreted and not reactive enough.

3. All Wales Core Palliative Care Service: Adult

A core palliative care service must be holistic and put the patient at its centre. It should be available to all those with a life limiting illness, including non-cancer conditions (such as renal and cardiac failure), in line with NICE guidance and the outcome of the review. It will:

- provide all patients with a 24hr service from generalists with access to specialist advice across all parts of Wales
- provide all patients with a comprehensive needs assessment undertaken by an appropriately trained professional
- provide patients with the necessary treatment delivered through an appropriate setting
- provide patients with detailed information about their conditions
- ensure services, specialist and general are of a recognised standard and well co-ordinated
- recognise the importance and contribution of community and primary care and independent hospice services
- provide good symptom management
- provide psychological, social and spiritual support
- endeavour to enable patients to die in the place of their choice and offer support to families and carers through the illness and into bereavement.

This can be achieved by having in place the following elements.

Specialist Palliative Care

The specialist Multidisciplinary Team (MDT) must nominate a **key worker**. The role of the key worker is to act as a co-ordinator and in an advocacy role for patients, carers and families. The key worker will have knowledge and experience of the palliative care process and ideally be a part of the MDT. An additional duty of the key worker should be to maintain links to the patient when care needs are less intense in order to provide continuity in the process.

The key worker will also be the link to other professionals linked to care, such as AHP support when needed, liaising with the patients GP or to care home staff.

In order to support the key worker in his or her role, a **directory of services** should be introduced for each commissioning area.

Care should be delivered through a **care pathway**, by a team comprising of the following elements:

- **Consultant in Palliative Medicine** (who specialises in palliative care. The consultant acts as lead for the team)
- **Clinical Nurse Specialist** working in the community and hospital settings (a registered nurse with specialist knowledge of palliative care)
- **Nursing team** (including community nursing, and with an agreed level of training in palliative care)
- **Rehabilitation team** (through physiotherapy, Occupational Therapy and agreed day clinic support)
- **Social Worker and Welfare Support Worker** (this will provide practical support such as access to equipment and information on rights and entitlements)
- **Administrative support team** (there should be a level of general administrative support to deal with reporting requirements, inputting data for IT systems, organising staff diaries and training and acting as a single point of access for the team)

The team should be supported by the following services:

- **Access to respite** (to provide and plan for minimum levels of respite support for families and carers in all settings and provide out of hours and emergency respite)
- **24/7 access to medication** (24hr access to a pharmacist or to medicines)
- **24/7 access to equipment** (including, where appropriate, joint stores and mechanisms to prevent delays in access for patients)
- **Access to specialist advice** (tertiary advice contacts must be available for advice and guidance on specialist medical queries including nerve blocks and spinal infusions)
- **Psychological support for staff** (a mechanism should be in place to enable access to support and counselling, especially in the case of generalist staff)

The team should also have links to **lymphoedema** services and to **bereavement** services, providing support and counselling, especially for bereaved children. However, this should not be funded as part of the Specialist palliative care team but be a separately developed and commissioned wider service for all those affected by bereavement or with lymphatic needs. Similarly, **complementary therapies**, although recognised as a valuable aspect of supportive care, should not be a component of a core service.

Delivery of care will inevitably involve partnership and links with both larger and smaller providers, such as day care facilities. Care does not need to be delivered in one setting only, and accessibility and convenience for patients should be considered when commissioning a provider of a service.

General Palliative Care

General support is also needed for patients. Currently, the majority of community support in Wales is delivered by Primary Care Teams. These teams should be adequately trained and have the necessary tools to ensure appropriate care at home whenever feasible. The level of community nursing service should be sufficient to allow all patients access to a **community nurse** with palliative care skills in their own home or care home setting, accessed via community or specialist palliative care teams.

Out of hours care must be supported by a **24 hour available service** with a single point of contact. This should be organised in a way that supports staff and does not place an excessive workload on them, recognising the requirements of the European Working Times directive. The staff on this rota must have knowledge of palliative care and access to support and advice through the directory of services.

An improved **unified IT system** needs to be in place with one record for patients that is accessible by all involved in a patient's care. This can be further supported by providing laptops to staff who work in the community or a telephone support line that allows staff to relay updated information for recording on the IT system.

An All Wales **training programme** should underpin the service, to be developed and overseen by an all Wales reference group on palliative care. With specialist teams undertaking a lead role in the education of their generalist professional colleagues.

4. Workforce Planning

Palliative care will be delivered by a wide variety of staff, from general to specialist. In order that they all work together effectively and smoothly as one unified service, it is important that their work and roles are structured and planned for.

Mechanisms must be in place to ensure effective partnership working and ensure continuity of service. All those engaged in a patient's care must have access to and be supported by the other professionals delivering the care. This is dependent on strong, recognisable leadership acting as a cohesive force.

Specialist staff must undertake a training and education role for all involved in the delivery of palliative care for example allowing them vocational experience in a Specialist palliative care setting.

General staff, including all staff working in partnership with the team to deliver the core service, must have an agreed level of accreditation and training. Workloads must allow for and recognise training needs, as agreed by an All Wales standard.

5. Quality Measures

The current clinical standards and guidance have been reported to be a good indicator of quality of service, for example NICE guidance and the all Wales Cancer Standards and tools such as the Gold Standards Framework. However, there was a feeling that the overall process was disjointed as there was no all Wales standard for palliative care applicable to all providers and no means to ensure the guidance is adhered to. This could be overcome by outlining the main principles of the existing guidance in **one all Wales document** including outcome measures (for example, choice of place of death).

There should be a **single regulating authority for inspection** of all core services to ensure all work to the same standard. The HIW and CSIW inspection regimes could form the basis for this in conjunction with a peer review process that would review practice against agreed clinical standards. These inspections must cover all clinical governance systems, and include facilities that provide inpatient and day care and nursing homes. All inspection processes must have agreed milestones in place for feedback, for example any reports to be sent to the organisation or facility within 6 weeks of inspection.

Presently, compulsory regulation applies to facilities with registered specialist beds. Regulation should be extended to **non-residential and generalist providers** of care, including nursing homes and voluntary sector facilities where they are delivering an element of the core palliative care service in accordance with a patient's care pathway. This role should be undertaken by the single regulating authority mentioned above, to ensure uniformity in clinical standards regardless of the place of care.

Training and education was a much advocated indicator and driver of a quality service. A training plan for professionals delivering palliative care in a generic setting must be drawn up annually, in line with an **all Wales standard for training**. A detailed programme must be developed and adhered to. This must apply to all general staff working in palliative care or with links to palliative patients with specific emphasis on District Nurses, GPs and care home staff and professionals providing out of hours support and general community support. This will include use of the All Wales Integrated Care Pathway for the Last Days of Life and basic symptom assessment and management.

Specialist staff will continue to maintain their skills through ongoing continuing professional development.

Patient, carer and family feedback is also widely recognised as an indicator of quality. Every patient or family should be given the opportunity to feedback on the care they are receiving. This can be done through user groups and discussions with families and carers. A structured **patient/carers diary** could be developed to gauge the views of patients, using a standard template so that feedback is structured and can be compared and analysed in order to inform service improvements and developments. This would avoid the feelings of overuse and imposition experienced by some when asked to complete regular questionnaires.

6. Commissioning

Under current arrangements, Local Health Boards are responsible for commissioning services. The practices between different LHB's on how this is done vary immensely. There is currently no uniformity in commissioning across Wales and very little stability. There is also disparity in joint working arrangements between social services and health and between neighbouring Local Health Boards.

For more specialised services, especially in the case of complex conditions, these services are commissioned by Health Commission Wales.

One of the major problems reported are regarding artificial boundaries created by the current process. **Pooled budgets** (between health and social services) can alleviate questions of 'who is responsible for paying'.

A move toward **regional planning** would be a further removal of boundaries between different geographical areas. This should be in line with existing networks to ensure a strategic link to needs based assessment.

Many patients access services cross border, and there are strong links and excellent joint working with English providers. Commissioning processes need to formally acknowledge these arrangements.

Commissioning should, in line with the Welsh Assembly Government report *Designed to Add Value*, involve the **voluntary sector** as an equal partner in commissioning discussions

Lead commissioning is another option, as is the case for funding Tŷ Hafan, but concerns were raised during the review over the level of control a lead commissioning LHB would have over the budget. The lead LHB should act as budget holder only with any final commissioning decisions requiring majority sign up or unanimous sign up, with support and guidance from the Regional Commissioning Units.

Linking commissioning to an All Wales standard will provide benchmarks for service levels that must be adhered to as part of the commissioning process. The concern with this approach is that this will encourage commissioners to only choose the services that meet this benchmark and do not deliver above it, and that commissioning will become money not quality driven. The possible result would be that higher quality but more expensive providers will be priced out of the market.

In order to avoid this, **expert commissioning** processes must be developed where palliative care specialists analyse which service would be most suited to a particular area or to serve a particular patient group. A mechanism for signing off commissioning proposals should be built in, and this can either be through;

- a) using the Regional Commissioning Units to approval final service specifications
- b) an All Wales commissioning panel that approves the final proposal

Agreements for service provision should be long term, over at least a **3 year funding cycle**. The current lack of stability means service providers report they are unable to plan let alone expand services. Grant funding should not be used to fund a core service, only for specific one off investment or pump priming.

7. Funding

7.1 Non-Commissioned Funding

The group recommends that there should be substantial additional funding to achieve and sustain a minimum core service level.

There are currently a number of funding streams outside of the commissioning process that can be targeted in a number of ways.

The All Wales Core palliative care service should be used as a basis for distributing additional funding to the voluntary sector in order to help them maintain their core functions. In the current climate, non-commissioned funding can allow independent providers to deliver care in line with the core service. This position may change in the longer term as more stable relationships are built up between commissioners and independent providers and long term commissioned funding agreements are put in place.

Funding should also be used to establish the core service set out in this report. This funding should be made available to all providers of the core service, both statutory and voluntary, in order to establish a level playing field across Wales. This would be determined in line with the local priorities of each multidisciplinary team.

However, during the course of the review a number of other options were considered. These are listed in **Annex 5**.

Government and local health bodies may still wish to develop services outside of the core palliative care service through grant funding. How that funding is targeted or distributed is not for the report to comment upon.

7.2 Continuing Healthcare Streams

There are reported problems with the mechanisms for accessing continuing healthcare funding, leading to delays in accessing equipment and services. This is often due to the complicated and cumbersome application forms, the requirement to repeat the whole process for each piece of equipment and confusion when interpreting guidance around what funding can be used for.

The current consultation on continuing healthcare funding guidance should include mechanisms for **rapid responses** in cases where funding has to be accessed immediately, more clarity over the role of social services and contributions from social services in the case of patients with more complex health needs.

With regards to accessing equipment through this mechanism, the **application process** for equipment needs to be refined so it is less bureaucratic. It needs to build in more flexible mechanisms so there is no need to complete the full application process for each individual piece of equipment. A forward planning mechanism needs to be in place so the process does not have to be repeated in its entirety when new equipment is needed.

Children and Young Peoples' Palliative Care

Children and Young People's palliative care

Children and young peoples' palliative care needs a different approach that adult palliative care. ACT/RPCH¹ guidelines estimate around 600 families across Wales have children with needs pertaining to life limiting conditions. However, figures suggest that only half (300 families) accessed hospices in 2005.

Ongoing work in the children's hospice movement seems to suggest, however, that these figures may be an underestimate and that the number in Wales is between 1000 and 1500. This would mean that not all families who could benefit from palliative care services are currently able to access it

Although there are a number of common themes regarding gaps in provision of care, the nature of the types of conditions and the age of the patient group means a different approach is needed when planning services.

Unlike adult palliative care, the majority of children and young peoples' palliative care deals with a long term, non-malignant and complex conditions. This means a different approach to service delivery than adult care.

The finding of this report echoed the existing recommendations and principles in the Children and Young People's Specialised Services project and the National Service Framework for Children and Young People. In order to achieve the core service standard, planning and commissioning must adhere to the standards set out by these two reports, specifically in relation to the staffing, quality and audit and transition for adolescents.

¹ The Association of Children's palliative care and Royal College of Paediatrics and Child Health

1. Background research

The main reports for consideration are those produced by ACT (the Association of Children's palliative care), the Children and Young People's Specialised Services project (CYPSSP) and the National Services Framework (NSF) for Children, Young People and Maternity Services.

The NSF is a 10-year strategy, launched in 2005, to transform services that relate to a child's development and wellbeing. It is cross-sectoral and sets national standards to improve and reduce variation in service delivery in the NHS and local government services that have an impact on the health and well being of children including, education, housing, leisure and transport. A review of the NSF will commence in the latter part of 2008.

The Children and Young People's Specialised Services Project (CYPSSP) was established in 2003 following the Review of Children's Specialised Services carried out by the former Specialised Health Services Commission for Wales (May 2002), now Health Commission Wales, to develop service specific standards for an identified group of 22 Children's Specialised Services for the children of Wales and to enable equity of access through effective managed clinical network models for all children and young people in Wales requiring Specialised Services.

As part of the project a standards document for paediatric palliative care was published for consultation in 2006. In addition there is a Universal Standards document containing relevant to all children and young people accessing specialised services which was published for consultation in 2005. The project is due to be launched in the summer of 2008.

The main points to be considered from the work that has been undertaken are:

- Children and young people often suffer from complex long-term conditions that require specialist levels of care.
- The approach to care must be holistic and consider the developmental needs of children, both emotionally and cognitively.
- Care must be family focussed and flexible.
- Many children now have a longer life expectancy due to medical advances, and as a result there are increasing numbers of adolescents with palliative care needs. These adolescents experience problems in the transition from children to adult services, as neither is suitable to meet their needs.
- Higher levels of community and home support are needed than in the case of adult service, including greater respite, to be delivered by a multidisciplinary team
- The multidisciplinary team should enable patients to die in the place of their choice and this wish is not always fulfilled.
- Sibling needs must be considered.
- Care pathways should always be used.
- Education and training of staff is vital to ensure quality of service.

2. Analysis of Consultation Responses and Workshops

Overview

There are excellent and much praised children hospice services serving Wales, with the South served by Tŷ Hafan and the North by Hope House/Tŷ Gobaith. Many children access services over the border through links with Alder Hey and Birmingham and South Wales has links to the Cardiff Children's Hospital. The cross border links are vital to the service. The flow of patients cross border needs to be monitored and information used to inform cross border commissioning and planning. However, it was felt that South West Wales needs a children's hospice service and a suggestion was made for establishing a hospice in the area.

Conditions are longer term, involve managing distressing symptoms and are often non-cancer. Many children have profound disabilities and need some form of stimulation, for example through touch and play therapies. There is a feeling of a lack of support and inequity of services for more complex conditions such as Duchene Muscular Dystrophy. Tŷ Hafan noted they are currently undertaking a mapping exercise of need that may inform future service planning.

A comfortable environment is important, so more services should be provided in the home. Children's wards are not an appropriate setting as they prove distressing not only for children with life limiting conditions, but for other children on the ward.

Access to Services

There are varying criteria for accessing care depending on which LHB area the patient lives in, with some receiving greater levels of care than others. Care should be delivered through a multidisciplinary team that provide a hospice and a home service, account for cycles of care and recognise changing needs for care.

Due to the nature of children's conditions, and considering a lot of day to day care is provided by the family in the home, more intense periods of respite are needed with medical input and must also be available out of hours and in cases of emergency, for example if a member of the family is ill.

An on call rota for qualified staff should be developed to support the multidisciplinary team and support out of hours care.

Staff Shortages and Gaps in Services

There are a lack of Children's Community Nurses, and some areas have no access to a Specialist Paediatric palliative care Nurse as there is only one working in the Gwent area at present.

Some Trust areas have no separate children and young people's service with no specialist support, which means more complex needs are not met. Renal services are affected by quality issues due to a lack of specialist knowledge in paediatric renal care.

There needs to be minimum of two paediatric palliative care Consultants for Wales. Currently, there is only one providing a tertiary service across Wales and this needs

to be increased to ensure all multidisciplinary teams have access to specialist advice when it is required.

There are problems around the funding and accessing of equipment, with Mid Wales noting problems with accessing specialist equipment for children with disabilities. Access to equipment is often limited and the process by which equipment is accessed leads to unnecessary delays. The process needs to be reactive and reflect the needs of growing children.

As many conditions are long term, the need for bereavement support and counselling for families and siblings is vital. Child psychology services should also be available for all patients in Wales. Staff working with children with life limiting conditions should also be ensured access to psychological support.

Joint Working

There is poor integration between health, social services and education. In order to provide a holistic and seamless service, networks need to be developed that include all those involved in the support and care of a child and their family. This could also include the police (as infant mortality often requires a routine post mortem). Co-ordination between services could be improved by ensuring a key worker is available to all families.

Technology

There is no IT system supporting the palliative care service in Wales. This needs to be developed so relevant up-to-date patient information can be accessed by all involved in a child's care.

Quality

The Wales Standards for palliative care Services and WAG Children and Young People's Specialised Services project provide the benchmark for service improvement and quality. These will be audited annually.

It is felt current audits, inspections and standards are sufficient and reflect a high quality of service. HIW inspected Quality Assurance programme, Care Standards, ACH (Association of Children's Hospices) quality assurance and benchmarks and HIW inspections against National Minimum Standards are detailed and ensure the delivery of high quality care.

Commissioning and Funding

Children's palliative care should be centrally commissioned, especially in the case of complex care packages. There also needs to be a better mechanism for accessing funding for lifelong palliative care packages, as these take too long to negotiate. Grant funding is unsustainable and long term funding is needed and health and social care budgets should be pooled

It was felt that the Continuing Healthcare mechanism is bureaucratic, misinterpreted and not reactive enough, with respondents reporting problems in accessing equipment and especially in accessing funding for end of life care. Stronger guidance is needed on continuing healthcare for children and young people to ensure it is responsive and does not act as a barrier to accessing care.

All Wales Palliative Care Planning Group Recommendations

3. All Wales Core Palliative Care Service: Children and Young People

A core palliative care service must be holistic and put the patient at its centre. In line with the Children and Young People's Specialised Services Project (CYPSSP) standards and National Service Framework for Children, Young People and Maternity Services (NSF), it should include:

- timely and open communication and information
- choices / Options in all aspects of care, including complementary therapies
- death in the place of choice
- co-ordination of services at home, where this is the chosen place of care, including a fully staffed Palliative Community Nursing Service
- expert symptom management
- access to 24 hour specialist advice and expertise
- emotional and practical support for all family members
- respite care, with medical and nursing input, when required

This can be achieved by having in place the following elements:

Specialist Palliative Care

The specialist Multidisciplinary Team (MDT) must be led by a **key worker** (*CYPSSP key action 2.3*). The role of the key worker is to act as a co-ordinator and in an advocacy role for patients, carers and families. The key worker will have knowledge and experience of the palliative care process and ideally be a part of the MDT. An additional duty of the key worker should be to maintain links to the patient when care needs are less intense in order to provide continuity in the process (*covered by NSF key action 2.14, 5.7*).

The key worker will also be the link to other professionals linked to care, including schools, Social Services and the Police (for cases of routine post mortem) and manage transition for adolescents. (*Transition key worker covered by NSF key action 5.33*)

In order to support the key worker in his or her role, a **directory of services** should be introduced for Wales, including local contacts. (*CYPSSP recommended*)

Care should be delivered through a **care pathway** (*CYPSSP key action 5.2, appendix 3*), by a team comprising of the following elements:

- **Paediatric Consultant (level 3)** (with access to tertiary advice and support)
- **Clinical Nurse Specialist** (a registered nurse with specialist knowledge of palliative care)
- **Community Paediatric Nursing support** (with a level of training in palliative care *in line with action 2.1 of the CYPSS project, NSF key action 7.4*)
- **Rehabilitation and Play Support Worker** (providing physiotherapy and touch or play therapies where appropriate) (*NSF 7.2*)
- **Social Worker and Welfare Support Worker** (this will provide practical support such as access to equipment and information on rights and entitlements) (*NSF/CYPSSP*)

All Wales Palliative Care Planning Group Recommendations

- **Administrative Support team** (there should be a level of general administrative support to deal with reporting requirements, inputting data for IT systems, organising staff diaries and training and acting as a single point of access for the team) (*Universal key action 2.1, 2.5*)

The team should be supported by the following services:

- **Bereavement and Counselling service** (to provide long term bereavement and counselling support to patients, families and carers including sibling support) (*CYPSSP key action 2.7*)
- **Access to respite** (to provide and plan for high levels of respite support for families in all settings and provide out of hours and emergency respite) (*CYPSSP key actions 1.4, 1.5, 3.3*)
- **24/7 access to medication** (24hr access to a pharmacist or to medicines) (*CYPSSP 3.7*)
- **24/7 access to equipment** (including, where appropriate, joint stores and mechanisms to prevent delays in access for patients) (*NSF key action 5.14*)
- **Access to specialist advice** – tertiary advice contacts must be available for advice and guidance on specialist medical queries) (*CYPSSP key action 1.2, 1.9*)
- **Psychological support for staff** (a mechanism should be in place to enable access to support and counselling, especially in the case of generalist staff) (*CYPSSP key action 2.8*)
- **Access to education** (in a school or home environment where staff are kept up to date on the child's condition and needs) (*NSF key action 7.7*)

General Palliative Care

As much support for children and young people will take place in the home (NSF key action 5.24), there needs to be a sufficient staffing level of **Children's Community Nurses** (*NSF key action 7.4, CYPSSP key action 2.1*) to allow all patients access to this service in their own home. These nurses must have a basic level of training in palliative care, with access to support from a Specialist Community Paediatric palliative care Nurse or Consultant support.

Transport to and from the home is a current area of concern as long waits can cause distress for children, especially for complex conditions and at the end of life. Changes need to be made to **ambulance** practices to prioritise the transfer of children with life limiting conditions. This needs to be reflected in improved targets for waiting times that are designed specifically for transfers from hospitals to the home or hospice, and for transfers to and from hospices.

As many children have complex and specialised needs, the team must be supported by the necessary medical expertise through **24/7 access to tertiary level advice and care**. (*CYPSSP key action 1.9*)

Out of hours care must be supported by a **24 hour rota** with a single point of contact. This should be organised in a way that supports staff and does not place an excessive workload on them, recognising the requirements of the European Working Times directive. The staff on this rota must have knowledge of palliative care and access to support and advice through the directory of services.

All Wales Palliative Care Planning Group Recommendations

A **unified IT system** needs to be implemented across Wales with one record for patients that is accessible by all involved in a patients care, including care provided outside of Wales. This can be further supported by providing laptops to staff who work in the community or a telephone support line that allows staff to relay updated information for recording on the IT system (*Action 3.1 and 5.4 of the CYPSS*).

An All Wales **training programme** should underpin the service, to be developed and overseen by an All Wales reference group on palliative care. This should include separate training for specialists and generalists, with specialist staff undertaking a training responsibility and be in line with Standard 6 of the CYPSS.

The implementation of the NSF and CYPSSP standards will ensure that the recommendations for the Core palliative care Services are largely achieved.

All Wales Palliative Care Planning Group Recommendations

4. Workforce Planning

Palliative care will be delivered by a wide variety of staff, from general to specialist. In order that they all work together effectively and smoothly as one unified service, it is important that their work and roles are structured and planned for.

Mechanisms must be in place to ensure effective partnership working and continuity of service. All those engaged in a patient's care must have access to and be supported by the other professionals delivering the care (*CYPSSP key action 2.6*). This is dependent on strong, recognisable leadership acting as a cohesive force. This must include staff who are responsible for the education of children with life limiting conditions, either in schools or through home tuition.

Specialist staff must undertake a training and education role for all involved in the multidisciplinary team, allowing them vocational experience in a Specialist palliative care setting. (*CYPSSP key actions within Standard 6*)

General staff, including all staff working in partnership with the team to deliver the core service, must have an agreed level of accreditation and training. Workloads must allow for and recognise mandatory training needs, as agreed by an All Wales standard. (*CYPSSP Standard 6*)

All Wales Palliative Care Planning Group Recommendations

5. Quality measures

The Children and Young People's Specialised Services project key actions can act as an indicator of quality and link to commissioning practices. **When delivering services, providers should adhere to the quality measures set out by the NSF for Children and Young People, specifically chapters 2, 5 and 7.**

The NSF has a web-based self-assessment audit tool (SAAT) that is used to monitor progress in implementing the NSF key actions and inform local service planning. Data is collected annually. In addition the CYPSSP key actions are specific and will be audited annually.

There should be a **single regulating authority for inspection** of all core services to ensure all work to the same standard. The HIW inspection regime could form the basis for this but with improved feedback procedures. These inspections must cover all clinical governance systems, and include facilities that provide inpatient and day care. All inspection processes must have agreed milestones in place for feedback, for example any reports to be sent to the organisation or facility within 6 weeks of inspection.

Presently, compulsory regulation applies to facilities with registered specialist beds. Regulation should be extended to **non-residential providers** of care, including voluntary sector facilities where they are delivering an element of the core palliative care service in accordance with a patient's care pathway. This role should be undertaken by the single regulating authority mentioned above, to ensure uniformity in clinical standards regardless of the place of care.

Training and education was a much advocated indicator and driver of a quality service. A mandatory training plan for all palliative care staff must be drawn up annually, in line with an **All Wales standard for training**. A detailed programme must be developed and adhered to in line with Standard 6 in the Children and Young People's Specialised Services Project.

Patient, carer and family feedback is also widely recognised as an indicator of quality. Every patient or family should be given the opportunity to feedback on the care they are receiving (*NSF key action 2.1, 2.2, 2.6, CYPSSP palliative care key action 4.4*). This can be done through user groups and discussions with families and carers. A structured **diary** could be developed to gauge the views of patients and families, using a standard template so that feedback is structured and can be compared and analysed in order to inform service improvements and developments. For children, this could be filled in by the family or main carer, engaging the child in the process where possible. For adolescents, a specific template diary could be developed for them to fill in that recognises the specific challenges they face.

All Wales Palliative Care Planning Group Recommendations

6. Commissioning

Under current arrangements, Local Health Boards are responsible for commissioning general services and Health Commission Wales are responsible for commissioning more specialised tertiary services, especially in the case of complex children's conditions.

There are, as with Adult palliative care, wide variations in practice among different Local Health Boards. The joint working arrangements between Social Services and Health is even more fraught due to confusion over responsibilities, often arising from Continuing Healthcare definitions. Many social services staff are reluctant to take on responsibilities for patients they see as having predominantly health related needs, meaning they do not always contribute to the funding of care packages.

Pooled budgets are needed between health and social services and a mechanism for funding contributions from education budgets where appropriate. Where regional commissioning may be most appropriate for adults, a move toward **central commissioning** with local input may be best for children's services as they are often for small numbers and are more specialised.

When the Regional Commissioning Units are fully operational, they will have a role in informing and developing commissioning processes for their particular area and informing the central commissioning process. The three units are in line with the existing network regions: South East Wales, Mid and West Wales and North Wales.

Many patients, especially children and young people, access services cross border, and there are strong links and excellent joint working with English providers. Commissioning arrangements need to formally acknowledge these arrangements.

Commissioning should, in line with *Designed to Add Value*, involve the **voluntary sector** as an equal in commissioning discussions

Linking commissioning to an All Wales standard will provide benchmarks for service levels that must be adhered to as part of the commissioning process. The concern with this approach is that this will encourage commissioners to only choose the services that meet this benchmark and do not deliver above it, and that commissioning will become money not quality driven. The possible result would be that higher quality but more expensive providers will be priced out of the market.

In order to avoid this, **expert commissioning** processes must be developed where palliative care specialists analyse which service would be most suited to a particular area or to serve a particular patient group. A mechanism for signing off commissioning proposals should be built in, and this can be through an All Wales commissioning panel.

Agreements for service provision should be long term, over at least a **3 year funding cycle**. The current lack of stability means service providers report they are unable to plan let alone expand services. Grant funding should not be used to fund a core service, only for specific one off investment or pump priming.

All Wales Palliative Care Planning Group Recommendations

7. Funding

7.1 Non-Commissioned Funding

The group recommends that there should be substantial additional funding to achieve and sustain a minimum core service level.

There are currently a number of funding streams outside of the commissioning process that can be targeted in a number of ways.

The All Wales Core palliative care service should be used as a basis for distributing additional funding to the voluntary sector in order to help them maintain their core functions. In the current climate, non-commissioned funding can allow independent providers to deliver care in line with the core service. This position may change in the longer term as more stable relationships are built up between commissioners and independent providers and long term commissioned funding agreements are put in place.

Funding should also be used to plug gaps in the core service set out in this report. This funding should be made available to all providers of the core service, both statutory and voluntary, in order to establish a level playing field across Wales. This would be determined in line with the local priorities of each multidisciplinary team.

However, during the course of the review a number of other options were considered. These are listed in **Annex 5**.

Government and local health bodies may still wish to develop services outside of the core palliative care service through grant funding. How that funding is targeted or distributed is not for the report to comment upon.

7.2 Continuing Healthcare Streams

The same issues regarding current continuing healthcare processes affect access to services for children and young people, with reports of particular problems with accessing emergency support for end of life care. Regarding the process for accessing equipment, this is especially important for children and young people. As children outgrow equipment quickly, the whole process has to be repeated when replacement equipment is needed. A continuous forward planning mechanism needs to be in place so the process does not have to be repeated in its entirety when new equipment is needed.

8. Transition and Care for Adolescents

The specific needs of adolescents and young adults will require further exploration that is beyond the remit of this report. Improvements in treatment and medication mean many children are living longer into adolescence and adulthood, for example patients with Duchenne Muscular Dystrophy and HIV/AIDS. Patients within this age group are faced with specific challenges associated with physical, emotional, social and cognitive development. These patients require care that meets and understands these needs within a comfortable setting that allows patients contact with their peers, as opposed to care within a setting geared to older adults or younger children.

Transition to adult services needs a multi agency approach, a clear definition of 'young people' and greater investment. Work must be undertaken to identify examples and, where available, solutions to this issue that will form the basis of a transition strategy for Wales.

ANNEX 1 - Working group

The members of the group are:

Chair: Vivienne Sugar, Chair, Welsh Consumer Council

Dr Andy Fowell Chair, All Wales palliative care Advisory Group

John Savage Executive Director, Nightingale House Hospice

Dr Richard Hain Senior Lecturer /Paediatric palliative care Consultant, UHW

Veronica Snow Lead Professional South West Wales Cancer Network

Dr David Salter Principal Medical Officer, Welsh Assembly Government

Dafydd Wigley Trustee of Hope House Children's Hospices

Dr Joanne Venables Consultant Paediatrician, Swansea

Working group activity

30th November Written consultation begins

5th December Webpage launched www.wales-consumer.org.uk/pcpg

11th December Second meeting of the planning group

- *background paper*
- *final arrangements for the workshops*
- *Oral evidence session on commissioning:*

Speaker

Peter Tebbit OBE (National Council for palliative care)

14th January Children and Young People's palliative care workshop Swansea (pm)

15th January Third meeting of the planning group

- *summary of consultation responses to date*
- *Oral Evidence session: Adult palliative care*

Speakers

Professor the Baroness Finlay

Ruth Treharne - Director, South East Wales Regional Commissioning Support Unit

Walter Brooks - Chief Executive, St Michael's Hospice

Hazel Cheeseman - Policy and Public Affairs Officer

Help the Hospices

- 28th January** Llandudno workshops
- Adult palliative care workshop (am)
 - Children and Young People's palliative care workshop (pm)
- 31st January** Written consultation ends
- 1st February** Adult palliative care workshop - Cardiff (am)
- 8th February** Adult palliative care workshop -Aberystwyth (am)
- 18th February** Fourth Meeting of the planning group
- *summary of consultations*
 - *summary of workshops*
 - *Oral Evidence session: Children and Young People's palliative care*
- Speakers**
- Katrina McNamara-Goodger - Head of Policy and Practice (ACT)*
- Patricia O'Meara - Paediatric palliative care Nurse Specialist*
- Jayne Saunders – Director of Care, Ty Hafan*
- 25th February** Final workshop report to be sent to members
Final consultation response analysis to be sent to members
- w/c 10th March** Draft report to be sent to group members
- 17th March** Fifth meeting of the planning group
- *presentation of final report for approval*

ANNEX 2 - Consultation Letter

Consultation on palliative care Services in Wales

The Minister for Health and Social Services, Edwina Hart AM, recently commissioned a planning group on palliative care in Wales. The purpose of the group is to establish a standard for essential palliative care services in Wales and a way by which quality of care can be measured. The terms of reference of the group can be viewed on our webpage (please see over for address).

We are asking for written submissions on what should be considered an essential palliative care service and should therefore be eligible for long term funding from the Welsh Assembly Government.

Due to the differences between children and adult palliative care services, we ask that you consider these areas separately and label your responses to reflect whether you are referring to an **adult** or **children and young people's** service.

We ask that you consider the following questions in your response.

- **What palliative care services should be funded by the NHS and/or Welsh Assembly Government and why?**
- **What services do you think should be funded by other means (i.e voluntary / private sector) and why?**
- **How can we measure the quality of these services?**
- **If you are a service provider, please give us a clear picture of the services you deliver, your experience (if any) of commissioning services and whether or not those services are readily available and sufficiently funded**
- *If you represent service users, please give us a clear picture of the range of services you are aware of and how accessible and easy to use that service is, for example how far away is your nearest facility and is it easily accessible?*

The closing date for responses is **31st January 2008**. If you wish your comments to be treated in confidence, you must clearly request that your response be treated confidentially. Any confidentiality disclaimer automatically generated in email responses will not be treated as such a request.

In addition to this written consultation, we will also be holding workshops across Wales in early 2008. The dates are as follows:

Adult palliative care Workshops

North Wales	28 th January	Llandudno
South Wales	1 st February	Cardiff
Mid Wales	8 th February	Aberystwyth

Children and Young People's palliative care Workshops

South Wales	14 th January	Swansea
North Wales	28 th January	Llandudno

Please indicate if you would be interested in attending either workshop to discuss your views and experiences in this area.

Please direct all submissions or queries to pcpg@wales-consumer.org.uk by telephone (029) 2025 5454 x224 or by post to:

Rebecca Thomas (palliative care Review)
Welsh Consumer Council, 5th Floor, Longcross Court, 47 Newport Road, Cardiff,
CF24 0WL

We will also post all details on our webpage, and this will include an electronic reply form and details of the workshops. This will be accessible from **5th December** on <http://www.wales-consumer.org.uk/pcpg>

For the Working Group to achieve its aim of providing the Minister with an evidence based system for future funding, it is essential that we hear from as many people as possible who have experience of the provision of palliative care in Wales. I look forward to hearing from you

Yours sincerely

Vivienne Sugar

Chair

palliative care Planning Group Wales

ANNEX 3 – List of written consultation respondents

1. Usk House Hospice
2. St David's Foundation Hospice Care
3. Beacon of Hope
4. Hospice of the Good Shepherd
5. Hope House Children's Hospices
6. Ty Hafan –Children's Hospice
7. St Anne's Hospice
8. George Thomas Hospice Care
9. Marie Curie Hospice, Penarth
10. St Kentigern Hospice
11. Paul Sartori Foundation
12. Shalom House
13. Hospice of the Valleys
14. St David's Hospice, Llandudno
15. Nightingale House Hospice
16. Help the Hospices
17. Association of Children's Hospices

18. Velindre Cancer Centre
19. North Wales Cancer Service
20. North Wales Cancer Network
21. South West Wales Cancer Network
22. South East Wales Cancer Network
23. Marie Curie Cancer Care
24. Macmillian Consultant (Paediatric)

25. North West Wales NHS Trust
26. North East Wales NHS Trust
27. Ceredigion NHS Trust (Bronglais Hospital)
28. Bro Morgannwg NHS Trust
29. Ceredigion & Mid Wales NHS Trust
30. Pembrokeshire & Derwen NHS Trust
31. North Glamorgan NHS Trust Specialist palliative care Team
32. North Glamorgan NHS Trust Paediatric palliative care Team

33. Social Care and Housing Services Torfaen County Borough
34. Caerphilly Teaching Local Health Board
35. Caerphilly Health Board
36. SW Wales Cancer Network
37. Velindre NHS Trust

38. National Assembly for Wales

39. Welsh Kidney Patients Association
40. Parkinson's Disease Society
41. British Lung Foundation

42. Wales Council for Voluntary Action
43. Age Concern
44. Royal College of Nursing

45. Chrysalis Trust
46. Crossroads
47. Swan Lake Project
48. Swansea Palliative Intermediate Care Team

49. Cardiac Networks Co-ordinating Group

50. Association of Community Health Councils

51. Cardiff LHB
52. Caerphilly LHB
53. Blaenau Gwent LHB
54. Pembrokeshire LHB
55. Carmarthenshire Local Health Board
56. Pembrokeshire and Ceredigion LHB

57. Bridgend County Borough Council
58. Flintshire County Council
59. Powys County Council People & Well Being Adult Service
60. Powys County Council People & Well Being Children's service
61. Bracken Trust, Powys

ANNEX 4 – Detailed overview of workshops

Mid Wales Adult palliative care Workshop

There were 18 attendees at the Aberystwyth workshop, ranging from Macmillan nurses, Citizens Advice Bureaux representative and medical directors.

Access to services

For Mid Wales, the rural nature of the area meant small numbers of staff covering large areas. Some nurses can only see 2 or 3 patients a day due to the amount of travelling. There is also a lack of nearby facilities and problems with transport. Some utilise volunteer transport schemes but these aren't common practice. In some cases, it may not be appropriate to transport patients so care needs to be deliverable in a local or home setting.

Access to equipment also proved problematic in some areas. Joint stores were used but were only open 9-5 and there is a 6-month backlog for assessments (Social Services). It was also felt the process could be changed so that it reflects continuity, and not stop and start for each individual piece of equipment.

There was a feeling non-cancer services were less well developed and that services needed to be developed for MS patients.

Gaps in Services

There is no full time palliative care Consultant post in Mid Wales and it was strongly felt this is needed not only for expertise but to provide leadership for the MDT. It was also felt this would attract skilled registrars and doctors to the area.

Access to Occupational Therapists and Physiotherapists was felt to be insufficient.

There is a lack of skilled, trained nurses and sub contracting to nursing agencies affects the quality and continuity of care.

There is a need for more administrative support for staff, especially nurses, as a lot of time is either spent travelling or with patients, leaving little time for anything else.

There is no child bereavement service in Powys and a lack of psychological support for carers.

For inpatient hospice services, patients have to travel over the border to Shrewsbury and Hereford.

Staff development and support

There was a call for better training, more opportunities to train and a general upskilling of staff. Someone needs to take the lead in driving up standards. Staff need to be given time off to participate in training and there needs to be continuous

education for GPs and nurses and in residential homes. There also needs to be greater psychological support for staff.

Out of hours services

The area is reliant on GPs, Nurses and Healthcare Assistants (HCAs) to provide out of hours care, and there is a fear that this can affect quality of service. Suggestions were made for a 24-hour rota of skilled staff.

IT / telehealth

Due to the rural nature of the area, many problems could be overcome through video conferencing and the use of technology. A unified IT system is needed that can be accessed by all service providers.

Joint working

Better joint working is needed between Health and Social Services, between different LHB areas and cross border. Services are currently working in isolation and there needs to be a more joined up approach and sharing of services.

Quality and standards

All services should provide the same quality of service. Education and training was felt to be a good indicator of quality

Funding and commissioning

It was felt LHBs do not have a great enough understanding of palliative care and this impacts of the quality of services they commission. Suggestions were made for central guidance, pooled budgets and a move to regional commissioning as a means to better planning and preventing overlaps in services.

Grant schemes are not sustainable and funding needs to be more long term. The groups gave examples of projects, such as Crossroads carer respite, that could not survive beyond short term grant funding as LHBs were unwilling to pick up the funding and it is often left to charities to continue funding of such schemes.

Concerns were raised over the forthcoming Trust mergers in the area and the effect this will have on services.

South Wales Adult palliative care Workshop

There were 55 attendees at the Cardiff workshop, with representatives ranging from nurses, consultants, hospices, carers and LHB staff.

Access to services

There needs to be equal levels of service for both malignant and non malignant conditions.

There needs to be a single point of access for services.

Patients need to be able to dip in and out of services as their condition improves or deteriorates, so greater flexibility is needed.

There must also be recognition of what services are available and how they meet need. Open dialogue is needed between patients and professionals to ensure they do not influence the care choices patients make.

The current social services referral process can affect discharge to the community/home.

There were concerns over planning for patients with dementia and some felt this would become an important issue for consideration in the near future.

Gaps in Services

Care packages not being fully met and community support varies. Strong leadership is needed.

District nurse numbers are being reduced and nurses, cover very wide areas. There is a shortfall in palliative care consultants and these are also stretched over large areas. There is also limited transport for patients to travel to facilities.

Greater levels of social care are needed in communities.

24/7 care is reliant on more general support and there needs to be a rapid response team available. It was reported Marie Curie is restricted in the care it is able to provide and is not always able to provide urgent care.

There are some problems accessing equipment and also a lack of beds to deal with complex, specialist needs.

Access to rehabilitation is limited, including access to Physiotherapist and Occupational Therapists.

There is a need for more Clinical Nurse Specialists and Specialist Oncology Nurses.

Some facilities are reliant on answering machines due to lack of staff.

There is a lack of funding for bereavement support and counselling. The multidisciplinary team also needs access to chaplaincy or some form of spiritual support.

Quality and Standards

Hospices are thoroughly regulated (CSIW/HIW), but there needs to be a common template across all services.

Existing guidance such as NICE guidance, Gold Standards Framework and the End of Life Care Pathway should always be used, in all settings and end of Life care needs to be more closely monitored. Outcome measures could be linked to these to ensure benchmarks outlined in the guidance are met.

Another useful measure is patient questionnaires and user feedback.

The competency of the voluntary sector needs to be viewed as equal to the NHS when commissioning services.

Staff development and support

Mandatory training is needed for care home staff, District Nurses, GPs and specialist nurses. There is a generic District Nurse (DN) programme being piloted in Cardiff to encourage DNs to see themselves as part of the palliative care team.

Education and training needs to be co-ordinated and funded by a central team.

Clarity is needed over terminology (i.e. what exactly is a Clinical Nurse Specialist).

It is difficult for staff, especially those in the community, to find time to train. It is hard to get general nursing staff released to train in palliative care and there is little access to training for Allied Health Professionals

One option could be to develop expert patients to help them cope with the system.

There needs to be more psychological support and current pressures affect the ability for nurses to go on leave, which in turn has a huge effect on staff morale and staff health.

Out of hours services

24/7 district nursing teams would be a sound basis for providing out of hours care.

As GPs provide much out of hours care, greater communication is needed between GPs and the palliative care team.

There are problems accessing medication and out of hours pharmacies are needed.

IT / telehealth

Unified Assessment Records and written records are cumbersome. The IT system needs funding in order to develop it and make it more effective.

Joint working

Cross boundary working between LHB areas is informal and reliant on goodwill.

Work between Social Services programmes and Health Services can frequently be disconnected.

The NHS and voluntary sector need to work more closely together.

Transition between general and specialist care needs to be seamless.

There is a feeling that GPs don't understand palliative care, and that they need to be integrated more into the process.

Funding and Commissioning

Separate health and social care budgets cause problems. There are too many LHBs and there are currently problems with cross border funding mechanisms. Commissioning should be done on a regional basis, jointly between social and health care.

Continuing care funding causes problems as the process is long and bureaucratic and leads to delays for patient care. It is not responsive enough. The budget for this needs to be pooled and mechanisms need to be in place for up front payment. Also health and social services professionals have different interpretations of the guidelines, so stronger guidance is needed. The positive aspects of continuing healthcare are indicators such as night care and respite.

Dorothy House Hospice in Bradford upon Avon was noted as a good example of commissioning.

The voluntary sector provide the added extras that they should continue to pay for and are happy to pay for.

A number of reviews have already taken place but nothing has changed.

North Wales Adult palliative care Workshop

There were 30 attendees at the workshop, including representatives from hospices, Local Health Boards, NHS Trusts, social workers, carer's organisations, nurses and domiciliary care.

Access to Services

There were concerns over whether there is an unmet need and not all who need services are aware of them or are accessing them, i.e. chronic conditions, dementia. Patients are not receiving the care they want and the current system cannot respond to need. Services also need to be flexible; to step up and step down according to individual need and referrals to palliative care need to be done early in the process.

palliative care needs to be for cancer and non-cancer. Due to the nature of non-cancer conditions, these are harder to plan services for.

Some services not 24/7 and not all have access to specialist support. Access to specialist care/beds out of hours is a problem as this means patients have to wait for them to become available.

Geography poses a particular problem, with limited access to services in remote areas. The poor public transport infrastructure affects access to services and alternative transport relies on volunteers.

There is a need for stronger leadership, and for a defined role for overall responsibility of palliative care. This could be role for district nurses in the community.

Gaps in Services

There is a lack of day services in the community. Day care could be provided by community hospitals, provided they have sufficient links to a specialist team.

Every team needs a key worker to act as coordinator.

Joint stores are used for equipment but there is a shortage of beds and mattresses with charities currently meeting the shortfall.

There needs to be greater support for carers as they often work full time as well as fulfilling their role as carer.

There is a lack of inpatient beds in area. This gap could be plugged by community hospitals (Flintshire).

There is no rapid response or 'palliative care A&E', this is partly due to a lack of beds.

Anticipatory care (i.e. support over Christmas) is growing but needs further development.

There needs to be more support in residential nursing homes for staff.

There needs to be a defined place for lymphoedema services.

More bereavement support is needed and remembrance services (i.e remembrance book). Arts and aromatherapy and other complementary therapies are good form of social support. These must be subject to risk assessments.

There should be greater support for families if care takes place at home.

There is a shortage in community nursing and no consultant to serve the Conwy area.

Quality and Standards

palliative care targets should be developed to monitor critical incidents and how many patients are on a care pathway when they die. Patients should be engaged more in end of life planning.

The tools that exist, such as Gold Standards Framework and NICE guidance, are not being properly utilised.

Patients, carers and families need to be engaged on how we can improve services.

Accrediting complementary services would be too problematic.

Internal education audits are needed.

Staff Development and Support

Specialist teams have a role in delivering education, and we need to educate staff in community hospitals to support specialists as well as other nursing staff.

Staff need to be educated on continuing care as there is often confusion over referral criteria.

A nurse psychologist could be used to support and mentor staff.

Forums can be used as support mechanism for carers. A directory of information could also be a useful support tool for them.

Greater clarity is needed regarding what is health and what is social care.

As care home staff turnover high, they are reluctant to release staff for training. This means no skill base is built up.

Out of Hours Services

There is not enough out of hours care, and the majority is covered by the GP, and out of hours care usually means covering huge areas. This is not ideal, as many have no continuity of relationship with patients. There needs to be a definition of when it is appropriate to use the GP and a service that allows for 24hr admissions and assessments. There is currently no 24hr district nursing in the area.

An out of hour's medication and prescriptions service should be available; this could be a district nurse role.

A 24/7 helpline manned by administrative staff could be set up to support healthcare workers.

24/7 respite is currently not available. Nursing homes could be utilised for some of this but there is a lack of emergency respite.

IT / Telehealth

There is poor information sharing and IT infrastructure. The CANIS cancer database does not allow for access to appropriate knowledge at the right time and reform should be linked to the unified assessment.

Joint Working

Services need to be better co-ordinated, with better links with Social Workers and better communication between Health and Social Services.

Funding and Commissioning

Funding is a constant problem as palliative care is not always a priority for LHBs. There is no discussion currently in commissioning process, and funding arrangements are often historical. Commissioning could be done through accredited specialist unit. Cost per bed could be starting point for funding, with a national or an individual tariff.

There is limited funding for specialist services and day care so these are not being developed.

Short term grant funding has implications for attracting staff to work in the area of palliative care there is uncertainty over whether a post can be funded past a 3 year period.

Continuing healthcare needs to be addressed and a fast tracking system brought in. Services are not ready in time to meet needs of deteriorating patients. This budget could be monitored and spend determined by a core CHC team.

LHBs should commission Marie Curie care to make it a more reactive service.

Complementary therapies should not be core funded.

South Wales Children and Young People palliative care Workshop

There were 23 attendees at the workshop, including paediatricians, community nurses, hospices, a parent representative and a school nurse.

Access to Services

Less children have cancer conditions and there are more long term conditions, often with complex health needs. These to be recognised as palliative and a scoping study of number of children with life limiting conditions should be commissioned as numbers are changing. Concerns were also raised over whether the needs of ethnic minorities are being met.

There is a lack of flexibility for recognising and adapting to changes in conditions. The approach to care must be holistic, including social workers, therapists, recreation and education. It is currently too focussed on physical health needs.

Regarding transport, often a child is physically limited so cannot travel far to facilities. There are few adapted taxis. There are waits for hospital transport and transport is an issue for respite. The social worker can access some funding for it, but this is not always possible. Car park payment has been another barrier to services

Transition for adolescents (14-17) is difficult, especially for continuity of care. Those 18+ don't want to go into adult hospices and access to education post 19 is non-existent as there are no specialist school places. Stronger leadership is needed in this area.

An acute hospital setting does not support the family and there should be more hospice care in community or a satellite service. However, providing services in a home or community setting has implications for workforce planning, as staff will need to build in time for travel arrangements. This has cost implications for service planning and could be the reason the service is less developed.

Currently, there aren't enough Children's Community Nurses, and this can result in unnecessary hospital admissions. A comfortable environment, such as the home, is important and can prevent unnecessary stays in hospital. Currently, there isn't enough flexibility in transition from ward to community setting.

Gaps in Services

Each Trust area should have its own Specialist palliative care team and community support across Wales is patchy. There is a shortage of children's community nurses, meaning that the service has to rely on bank nurses who aren't trained for palliative needs. Rural areas need a mix of one to one and telephone support.

There is a need for intensive support in last 48 hrs of life, including a sitter service and for ventilated children, who have additional needs.

More bereavement support and more sibling support is needed, including post bereavement support. Charities provide the majority of leisure services and family and sibling support, but not enough to meet need.

A one-stop shop for information on financial support for families would be useful. There is limited access to social workers, with health workers often providing the support. Key workers, if funded long term, could also provide an advocacy role as well as a co-ordinating one.

Tŷ Hafan provide much in way of equipment and facilities. Access to equipment is vital, and different services need to work together to provide this (i.e. adaptations in schools). There is currently a shortage, especially for wheelchairs. Children grow quickly so new equipment is often needed. The social services assessment is bureaucratic and there may not always be enough funding for the equipment. Some families have to buy their own, as they simply cannot cope without it. Schools get donated equipment and REACT² are able to provide immediate equipment.

Tŷ Hafan also provide a respite service but the level of residential and out of hours respite and Local Authority funded respite needs to be increased.

There is limited access to home tuition for children and young people.

Staff Development and Support

Staff should have access to more psychological and bereavement support. Many are working above expectations, experience high sickness due to stress, work unsociable hours and do not have enough access to training and support.

Key workers and Children's Community Nurses need to work with schools to educate staff.

Concerns were raised over the level to which GPs are trained. It was felt there should be more named GPs with an interest in children's palliative care who are encouraged to gain qualifications in this area, for example through the Cardiff University course in palliative care, which has a paediatric module.

Quality and Standards

Current standards and guidance in children's palliative care include Benefit Wales, ACH, HIW, National Service Framework for Children and the Liverpool Care Pathway and ACT pathways, but there is no measuring of service levels and no benchmarks for service levels. The choice of place of death should be a target that is always met.

Targets could be a means of attracting more funding from Trusts. However, measurable outcomes difficult are to assess, e.g. sufficient levels of sibling care.

There is a lack of feedback to staff, limiting opportunities for service improvement. Mechanisms could be put in place for this.

Out of hours services

There is no 24/7 medical cover across Wales. 24/7 care is provided by Tŷ Hafan including outreach, but there is no emergency respite. Out of hours could be better

² **Rapid Effective Assistance for Children with Potentially Terminal Illness** is a charity for financially disadvantaged children

supported by 24hr telephone support to help people access services/prescriptions etc.

There is no official 24hr specialist paediatrician. Wales needs two, one for North and one for South Wales.

24hr rota nurses have been used, but this has been dependent on goodwill. District nurses refuse to provide this care as they are not qualified enough. There is need for a on call rota of qualified able professionals.

IT / telehealth

An IT system is needed to support out of hours services and ensure that relevant up to date patient information can be accessed by all.

Joint working

Cross boundary working is restricted by the current system. This could be aided by a palliative care Nurse Bank shared across boundaries, with close links with a Community Paediatrician.

Communication between services is poor and there must be better palliative care networks, including palliative care paediatrician networks, links to Education, Social Services and the Police. Social Services don't always contribute as they see children as health responsibility due to their complex needs. Police should be a part of the network as infant mortality often requires a routine post mortem. District and community hospitals also need to be made aware of networks so they can have access to a good level of specialist support.

There is not enough communication between departments for inpatient appointments, so appointments are not always planned for the convenience of the individual patient. Transport is difficult so it would be beneficial to have all appointments close together. This could be a role for a key worker.

Funding and commissioning

LHBs are difficult to get funding from and money is not get directed where it is needed, for example LHBs may refuse to fund some equipment. Pooled budgets would be a step forward and the palliative care team should be centrally funded.

There is a lack of guidance on funding and accessing funding. More clarity is needed on end of life care and continuing healthcare criteria. Continuing healthcare is a time consuming and rigorous process and is not reactive enough. Some end of life care funding will be fast tracked, but more often it is discussed at fortnightly or monthly meetings. There also needs to be better mechanisms for lifelong palliative care packages, as these take too long to negotiate. More funding is also needed to support care at home.

The voluntary sector fear a loss of flexibility with 100% funding, but a third funding would provide some stability. Treats, holidays and complementary therapies should remain outside central funding.

North Wales Children and Young People palliative care Workshop

As there were only 3 attendees, this workshop was used as an expert evidence session between group members and the attendees, who worked in both community and hospice settings.

Access to Services

There are an estimated 600 families in Wales with palliative care needs. Good links with maternity wards means children with palliative needs are identified early. Tŷ Gobaith (Conwy) and Hope House (Oswestry) provide a lot of services for North Wales. However, there are psychological connotations with the word hospice, which means not all families will wish to access services through their facilities.

Services need to be developed on both a national and local level. More money is needed for services in rural areas and those with a more problematic geography.

Gaps in Services

End of life homecare is heavily dependent on charitable funding at present.

Community care is often provided by CLIC Sargent nurses³. Diana nurses can deal with patients with complex needs. Some provide 24hr care but this is above and beyond what they are funded for. There is a shortage of Paediatric Palliative Community Nurses in Mid Wales.

Respite needs to be supported by specialist clinical staff as many children have complex health needs and needs to be for longer periods (at least 13 days per year) than adult respite (13 days overall). Diana and CLIC nurses can provide this support in the home and Tŷ Gobaith and Hope House provide an outreach nurse to help with some procedures. Acute wards are not a suitable setting.

In the case of children and young people, social work and bereavement is a long term process, sometimes over a decade. This must include sibling support.

There is seldom continuity for families in respect of social care and advocacy support, due to a large turnover of social support staff. Advocacy services are especially important for some working class families who aren't aware of rights and entitlements.

There is only one paediatric palliative care consultant for Wales. There needs to be one for North and one for South Wales.

Staff Development and Support

NHS training is provided to community teams but counselling and psychological support for staff must be improved.

³ CLIC Sargent is cancer charity providing care for children and young people and their families

Out of Hours Services

The hospice provides a 365 day service. CLIC and Diana provide end of life care services in the home, but have to claim funding retrospectively for this. Diana nurses often give out their home phone number for emergencies, and out of hours GPs act as referral contacts for care.

Joint Working

Children's services are shared with North West of England and with Alder Hey, so there are good cross border links.

Joint working between services is less co-ordinated, and patients are often passed between health and social care. This is time consuming and leads to delays in accessing funding. Overall however, there is good partnership and a good level of services in community.

Quality and Standards

Children's services closely are regulated by HIW, child protection arrangements and the Children's Act. This means a very high quality of service. However, this is a more costly service meaning commissioners are reluctant to pay. Quality doesn't need to be linked to funding it is already sufficiently controlled by the existing frameworks.

Funding and Commissioning

A way of redistributing current funding could be to reduce the numbers of beds on children's wards and redirect funding to community services, as there is a heavy dependence on charitable funding in mid Wales for this service.

Funding is rarely long term and grant funding is unstable. Some providers even reject grant funding as they know they can't maintain the service past the life of the grant. This makes expansion of services problematic. There needs to be long term, preferably ten year, funding as the cycles of planning need are longer in children's palliative care.

LHBs have an aversion to innovation and risk taking and often refuse to fund new services. There are no commissioning arrangements in place with LHBs in the area and there is too much bureaucracy for the small amounts of money received from LHBs. Service Level Agreements aren't negotiated or based on need. Any targeted investment needs to be used wisely, i.e. tackle waiting times. The commissioner needs to control this and ensure services reflect need and availability. Regional commissioning may be a better option, with collated contributions from the LHBs.

The transition from children to adult services needs investment.

Providers do not want 100% state funding, but a set percentage of costs should be funded. Full cost recovery would be too problematic but a suggestion was made to base the percentage on core nursing service numbers. This would equate to around 20% of overall costs and could be eventually built up to 30%. Using nursing would avoid geographical issues.

More capital is needed for start up and must be supported by continuous 20% revenue funding.

ANNEX 5 - Non-recurrent Funding Formulas

• *Achieving a baseline percentage of funding costs - Scotland*

In Scotland, the grant for independent hospices was distributed on the basis of meeting 50% of the running costs of the service. This allows the provider sufficient independence to determine how they plan and develop their own services while providing a core level of stability. There is year on year uplift, meaning slight fluctuations in the coverage percentage. So far, the Scottish Government have reported satisfaction with the arrangements. However, this has no link to quality indicators and no assurance of quality.

As Welsh hospices are starting from a low basis of funding, long term investment would be needed to bring Wales in line with the Scottish model. However, further work would need to be done to determine what an appropriate percentage would be for Wales and how much investment would be needed. This was not possible within the timescale of this review.

• *Achieving a baseline percentage of funding costs – Nursing staff*

Hope House children's hospices provided a worked example for funding based on 50% of the cost of employing qualified nursing staff. This would equate to around 20% of total care costs for the overall service.

Worked example based on actual hospice costs⁴

- Expenditure on holistic palliative care for Welsh children and families: £1,566,000
- Expenditure on qualified nursing staff (Welsh children only) £750,000
- 50% of qualified nursing staff expenditure £375,000
- ***(This constitutes the target total NHS support grant)***

LESS:

- WAG grant towards Direction Employers pension contributions £25,000
- LHB contributions to the hospices £47,000
- Central top-up grant from WAG required to reach target level £303,000

Total % NHS contribution to cost of service delivery: 19.5%

• *Target identified priority action areas*

Another option is to identify priority areas, as arising from the findings of the report, and stipulate that any additional funding be used to develop services in these areas. This would be a move towards achieving a core service level, but would remove any flexibility for priorities to be determined at a local or regional level.

⁴ Using the above figures, should the LHB's find they are able to increase their level of support to, say, £75,000 the target support level remains £375,000 (50% of the cost of employing qualified nursing staff), leaving WAG to provide a central support grant of £275,000 instead of £303,000.

- *On a formula basis only*

Another option is to distribute the grant in line with a set formula, such as a national tariff, cost per bed or based on activity such as nursing levels. An example of some formula options are:

A tariff for services

This model of funding is based on the Payment by Results (PBR) system which has been used in the English health system. Although PBR is not being used in Wales the principle of determining a consistent price for defined services that local commissioners then use in locally drawn up contracts is something that could realistically be applied in Wales.

The system essentially creates a national tariff for similar healthcare services (e.g. cost of a palliative care inpatient bed) and, in theory, it can be applied across all settings. This has the advantage of consistency and transparency. However, one of the challenges of this model is that where there is no extra funding in the system the impact is likely to be that local commissioners commission lower volumes at the set tariff rather than fund a greater proportion of services.

To be effective, there must therefore be clear commissioning guidance, investment and possibly model contracts to accompany a move to a tariff based solution.

Although work has been undertaken in England on costs for specialist palliative care there are still gaps for much of the care that hospices provide, and, in particular, hospice at home and day care services.

Funding outcomes

There are key outcomes that people want to achieve through their care at the end of life and there are mechanisms for measuring whether these have been achieved.

<i>Outcome</i>	<i>Measure</i>
<i>Physical relief from pain and other symptoms</i>	<ul style="list-style-type: none"> • <i>Existing measures of symptom control</i> • <i>Welsh/ Liverpool Care Pathway audit</i> • <i>Meeting clinical standards</i>
<i>To be treated with dignity and respect</i>	<ul style="list-style-type: none"> • <i>VOICES survey</i> • <i>Meeting Preferred Priorities in Care</i>
<i>Coordinated services which meet their needs</i>	<ul style="list-style-type: none"> • <i>evidence of holistic advanced care plan</i> • <i>audit of patient journey</i>
<i>Emotional and spiritual support for patients and their families</i>	<ul style="list-style-type: none"> • <i>VOICES survey</i> • <i>Patient measure?</i>
<i>Good information and communication</i>	<ul style="list-style-type: none"> • <i>evidence of holistic advanced care plan</i> • <i>documented conversations</i>

ANNEX 6 – EXAMPLE OF CARE PATHWAY

NAME
ADDRESS
DOB

SURGERY
GP/Consultant

Care Pathway for the last days of life

(based on the Royal Liverpool University Hospitals' ICP for the dying patient)

The Care Pathway is intended as a guide in providing care for the patient and their family in the last days of life. As a multi-disciplinary document it will replace existing medical and nursing notes during this period of care.

Each professional is encouraged to exercise their own professional judgement.

Any variances to the care suggested in the Pathway should be recorded.

INSTRUCTIONS FOR USE

1 Initial Assessment should be completed as the patient is entered onto the Pathway. The Doctor completes page 2 {yellow sheet}. The nurse completes page 3 and 4 {green sheet}.

2 Ongoing Assessment. Page 5 to be completed by the nurse when visiting and page 6 every 24hrs. New sheets of pages 5 and 6 {blue} should be used each day.

3 Variance occurs if the Pathway is not followed as expected. Any variance should be recorded on the pink sheet. An answer in *Italics* is a variance.

N.B. a variance is not wrong but it is important to record to help with audit.

4 Multi-disciplinary Communication Sheet {white sheet}. Allows scope to record anything not covered by the Pathway. It's use should be encouraged to record communication with the patient and family.

Option of discharge/transfer has been considered Y[] N[]

CRITERIA FOR ICP - DO NOT PUT ON PATHWAY UNLESS Patient will be dying and at least two of the following:

Bedbound []

Semi-Comatose []

Only able to take sips of fluid []

No longer able to take tablets []

G.P has been informed of situation Y[] N[] (white)

CPR has been discussed with relatives and agreed to be inappropriate Y[] N[]

Patient Not for CPR YES []

**** Advanced Directive of Living Will Y[] N[]**

**** Discussed with relatives, Macmillan / Marie Curie services available Y[] N[]**

NAME
DOB
D No. Date.....
Time.....

DOCTORS ASSESSMENT

Diagnosis

PHYSICAL CONDITION

Y N

Conscious	<input type="checkbox"/>	<input type="checkbox"/>
Able to swallow	<input type="checkbox"/>	<input type="checkbox"/>
Aware	<input type="checkbox"/>	<input type="checkbox"/>
Nausea / Vomiting	<input type="checkbox"/>	<input type="checkbox"/>
Confused	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>
Agitated	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Distressed	<input type="checkbox"/>	<input type="checkbox"/>
Continent	<input type="checkbox"/>	<input type="checkbox"/>
Dyspnoea	<input type="checkbox"/>	<input type="checkbox"/>
Catheterised	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory Tract Secretions	<input type="checkbox"/>	<input type="checkbox"/>
Other state		

MEDICAL MEASURES If a box in *italics* is ticked explain action / inaction on variance sheet.

Goal: Current medication assessed and non essentials discontinued

Appropriate oral drugs converted to subcutaneous route via syringe driver

Yes No

Goal: PRN written up for list below - as per Protocol

Pain - Analgesia Yes No

N&V - Anti-Emetic Yes No

Agitation - Sedative Yes No

Respiratory Tract Secretions - Anticholinergic Yes No

Syringe driver Yes No

Goal: Discontinue inappropriate interventions

Blood Tests Yes No

Antibiotics Yes No

Doctors signature _____ Date _____

Print name _____

On call GP informed Yes No

(yellow)

NAME

DOB

Date.....

Nursing Assessment

COMFORT MEASURES.

Goal: To promote patient comfort

Pressure areas assessed Yes [] No []

Assessed need for: special mattress Yes [] No []

Assessed condition of mouth Yes [] No []

Assessment of wounds Yes [] No []

Action taken on any of above assessments

Consider the environment: comfort, safety, temperature, ventilation.

COMMUNICATIONS

Goal: Ability to communicate assessed

Languages spoken _____ Preferred language _____

Barriers to

communication _____

Goal: Identify and address patients fears and anxieties

Patient recognises that they are dying Yes [] No [] Don't Know []

Fears identified:

RELIGIOUS / CULTURAL REQUIREMENTS

Goal: Religious and cultural needs are respected

Religion identified (please specify) _____

If appropriate contact made with Minister Yes [] No []

Contact name _____ Contact number _____

Religious / Cultural needs identified - please state (green)

BEREAVEMENT PLANNING / FAMILY CARE

Goal: Fears and anxieties of relatives identified and addressed

Family recognise that patient is dying Yes [] No [] Don't Know []

Plan of care discussed with relative: Yes [] No []

Fears identified, please state

Nurses signature _____

Date _____

Print name _____

(green)

Name Date

DOB

CODES [please enter in columns] **A-goal achieved V-goal not achieved**
record on variance sheet N/A-not applicable

PATIENT PROBLEM / FOCUS ASSESSMENT SYMPTOMS

1 PAIN

Goal: Patient is pain free

Verbalise by patient if conscious

Pain free on movement

Appears peaceful

Move only for comfort

2 AGITATION

Goal: Patient is not agitated

Patient does not show signs of delirium,

terminal anguish, restlessness.

Exclude retention of urine as cause.

3 NAUSEA AND VOMITING

Goal: Patient does not feel

nauseous

or vomits

Verbalised by patient if conscious

4 RESPIRATORY TRACT

SECRETIONS

Goal: On observation patient

does not have "rattling"

secretions

5 OTHER SYMPTOMS

Symptom[s] _____

Goal: _____

6 MOUTH CARE

Goal: Mouth is moist and clean

7 SYRINGE DRIVER

Goal: Medication is delivered

safely

and accurately

Signature of named nurse

Time of Visit

For 1-4, refer to attached Protocol for guidance.

Repeat this page every 24hrs. (blue)

Complete Daily

MOBILITY / SAFETY

Goal: Patient safety ensured

Supervision required

Assessed for bed aids as appropriate

MICTURITION DIFFICULTIES

Goal: Patient is comfortable

Urinary catheter if in retention

Urinary catheter or pads, if general weakness creates incontinence

COMMUNICATION

1 PATIENT

Goal: Patient becomes aware of situation as appropriate

If appropriate, patient is given opportunity to express concerns

Patient is informed of procedures

Touch, verbal communication is continued

2 FAMILY / OTHER

Goal: Family / Other are prepared for the patient's imminent death

Check understanding

Inform of measures to make patient comfortable
opportunity given to express fears and concerns

<p><u>Day</u></p>

DAILY REVIEW BY TEAM If a box in *italics* is ticked explain action / inaction on variance sheet.

Goal: All appropriate medications given as prescribed

Non essential medication discontinued Yes [] No []

Goal: Inappropriate interventions discontinued Yes [] No []

RELIGIOUS SUPPORT

Goal: Religious rituals / support have been performed

Before dying Yes [] No [] N/A []

Whilst dying Yes [] No [] N/A []

Named nurse signature _____

Repeat this page every 24 hrs

Day
(blue)

NAME

DATE and TIME OF DEATH

CARE AFTER DEATH

GP informed of Death Y[] N[] Time.....

DEATH CERTIFIED

Signature of Certifier
Time

FAMILY

Goal: To prepare, inform and support the patient's family /other, during final stages and immediately after death

Post mortem discussed if appropriate Yes [] No []

Contacting Funeral Director explained Yes [] No []

Information sheet given Yes [] No []

Family support present Yes [] No []

PATIENT

Goal: Special needs identified

Patient had recent administration of radio-isotope: *If yes*, Yes [] No []

Nuclear Medicine is informed and guidance followed Yes [] No []

Family and Funeral Directors informed Yes [] No []

Patient had infectious disease: *If yes*, Yes [] No []

Funeral Directors and home loans informed Yes [] No []

Patient has religious needs Yes [] No []

Signature of Nurse

Please inform relevant out of hours agencies of patient's demise (see page 1b for phone number)

Variance Sheet Copied and Sent to: Ros Johnstone, palliative care Department, Bodfan, Eryri Hospital Caernarfon, Gwynedd LL55 2YE Yes [] No []

Name: _____ M□□ F□□	CONSULTANT	HOSPITAL
Address _____ _____ _____	GP	WARD
D.o.B. _____ D No _____	NAMED NURSE	AREA

SYRINGE DRIVER

G.P./Consultant										
GRASEBY M.S.16A. BLUE RATE SET = mm per hr				GRASEBY M.S. 26 GREEN RATE SET = mm per 24 hrs						
COMMENCED BY.(Nurse/Doctor)					Signature			Signature		
DATE										
TIME SET UP / CHANGED										
RATE SET AND CHECKED										
SOLUTION CLEAR										
PRIMED NEW LINE										
CONNECTIONS SECURE										
NEEDLE SITE EXAMINED. ENTER RATING										
AND ACTION TAKEN (see * below)										
LIGHT FLASHING										
SPARE BATTERY AVAILABLE										
BREAKTHROUGH ANALGESIA										
PRESCRIBED (see guides no)										
COMMENTS										
SIGNATURE										

* = RATING:- 1 = CLEAN 2 = RED 3 = INFLAMED ACTION TAKEN = e.g. NEEDLE SITE CHANGE
(white)

Guidelines for Symptom Control

Syringe Drivers are not always necessary, but are extremely useful if patient:

- nauseous or vomiting
- unable to swallow
- too weak for oral drugs
- unconscious
- has poor oral absorption

All the drugs in the guidelines are compatible in mixtures in a syringe driver.

Precipitation may occur with higher concentrations of Cyclizine.

Water for injection to be used to dilute all drugs except methotrimeprazine (use 0.9% sodium chloride)

Pain

Is the patient able to swallow medication?

If **yes**:- Continue oral s/r morphine + 1/6th dose for breakthrough pain

If **no** Convert to SYRINGE DRIVER

Calculate 24hr intake of Morphine.

Divide total by 3 to get the equivalent dose of Diamorphine s/c over 24hrs

E.g. patient on 60mg MST bd and had 2 doses of 30mg Oramorph

total (60 * 2) + (30 * 2) = 180mg

Equivalent dose of Diamorphine = 180/3 = 60mg

Also needs breakthrough dose prescribing of 1/6th of syringe driver i.e. 10mg Diamorphine in this example.

If not previously on strong opioid:

Bolus Diamorphine 2.5-5mg s/c

Syringe driver 10-20mg s/c Diamorphine over 24 hrs

PRN Medication - 2.5-5mg s/c Diamorphine

To calculate subsequent dose of Diamorphine:

Add the dose of Diamorphine given in the previous 24hrs.

I.e. Syringe driver plus prn doses..

Increase the syringe driver dosage accordingly.

At the present time (May 2005) Diamorphine may be difficult to source, Morphine is available in 10 and 30mg per ml ampoules and can be used with other drugs in a syringe driver. To convert from oral Morphine to sub cut Morphine divide by 2. In the above examples there would be 90mg of Morphine in the syringe driver and 15mg as a breakthrough dose.

If pain persists consider other causes of distress: bone pain, neuropathic pain, anxiety, fear, full bladder.

(white)

Nausea and Vomiting

PRN medication on all treatment sheets: Cyclizine 50mg s/c bolus 6hrly

If nauseous or vomiting:

Cyclizine 150mg s/c via syringe driver over 24hrs.

If problem persists:

1. Add Haloperidol 5mg to syringe driver over 24hrs
2. Replace above drugs with Methotrimeprazine 25mg over 24hrs
3. Contact palliative care Team

If bowel obstruction present: contact palliative care Team.

Restlessness, Agitation, Anxiety

All treatment sheets to have PRN Midazolam 5-10mg s/c

If patient is restless:

- Add 20mg Midazolam to Syringe Driver over 24hrs
- Give 5-10mg Midazolam 2hrly PRN

The dosage in the Syringe Driver can be increased if needed in 50% increments to a maximum of 100mg

Noisy Breathing due to Respiratory Tract Secretions

All treatment sheets to have Hyoscine Hydrobromide 0.6mg s/c 4 hrly written up.

If present give:

- Hyoscine Hydrobromide 0.6mg s/c bolus
- Add Hyoscine Hydrobromide 1.2mg s/c to syringe driver over 24 hrs.

If Symptoms persist increase Hyoscine Hydrobromide to 2.4mg (in 24hrs)

Further details available in Trust Formulary, or BNF pages 12-15

These guidelines are based on:

Changing Gear: National Hospice Council 1998

All Wales Palliative Medicine Guidelines 1998

Useful Telephone Numbers

palliative care Dept.

01286 662775

Health Authority Nominated pharmacies

Dr A Fowell and L Minto

Ysbyty Gwynedd

September 1999

(white)

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